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Collaboration Therapy: Telehealth Principles and Case Studies

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Abstract

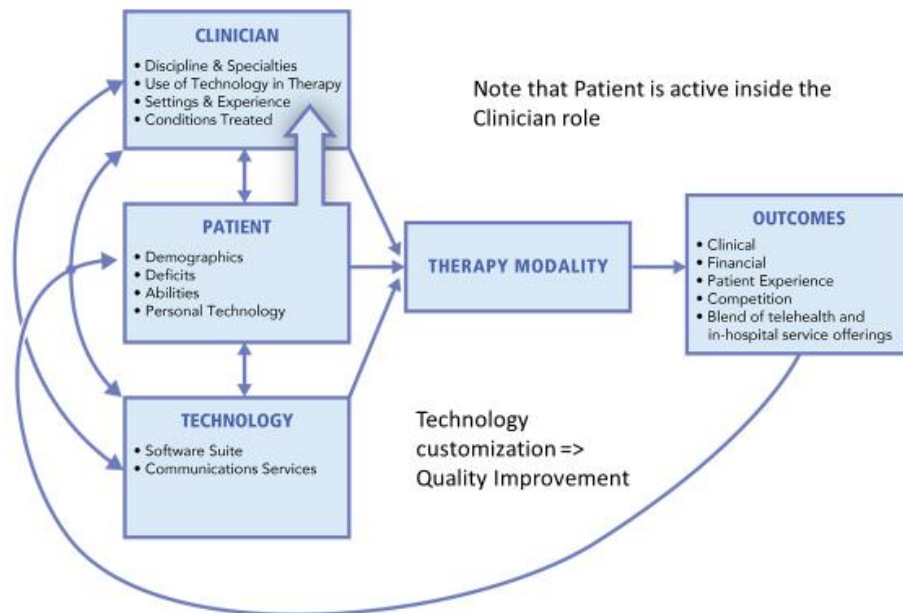
While conventional in-clinic Traumatic Brain Injury (TBI) rehabilitation serves the needs of the vast majority of patients many of whom go on to resume their lives a significant percentage of patients continue to have enduring cognitive disabilities despite long-term and skilled therapy. However, these patients can rapidly achieve gains which typically continue to increase toward substantial self-sufficiency when engaged in Collaboration Therapy (CT). CT is directed toward patient populations appropriate for a telehealth service who meet the following criteria: 1) patients have plateaued in conventional in-clinic therapy; 2) in-patients are too distant from an appropriate outpatient facility; and 3) individuals with TBI/ABI (acquired brain injury) are in unserved or underserved geographical areas. CT telehealth service is also valuable for High Achieving individuals – by occupational, avocational or educational achievement – who will often have difficulty with conventional rehabilitation. This paper describes CT, telehealth and presents seven case studies that provide context and detail to the CT model and outcomes.

Introduction

The Institute for Cognitive Prosthetics (ICP) has developed a telehealth delivery system for treating patients with cognitive deficits from traumatic brain injury (TBI) and some with non-degenerative acquired brain injury (ABI). To be effective in a clinical service, a delivery system needs to enable the therapist to address a broad range of problems that a patient may present. Collaboration Therapy (CT) is a novel telehealth delivery system (Figure 1) that addresses a very broad range of cognitive problems and issues. Functional Rehabilitation a model of brain injury rehabilitation that uses everyday activities as the content of therapy, but the activities need not necessarily be relevant to the patient's everyday life or salient to the individual. CT falls within the Functional Rehabilitation model but expands it, in that the activities addressed in therapy come

from activities *important to the patient*, especially activities tied to an upcoming event.

Figure 1. Collaboration Therapy Model



The Collaboration Therapy (CT) model is a learning system (Starr, 2020b) with **inputs** consisting of the *therapist* located in a clinic, *patient* located remotely in their natural environment, for example at home, work or in school, and computer-based *technology*; a **technology process** shared by the therapist and patient that integrates and supports the therapy and the teaching-learning relationship between the therapist and patient. In CT, therapist and patient are both active in guiding the therapy which produce the **outcomes**, i.e., achieving clinical and other results. As a socio-technical system, the outcomes produce **feedback** for the therapist and patient.

CT technology can be fashioned to create new opportunities for therapist and patient to work together, expanding therapeutic options. Four technologies, described below, create the opportunity for Collaboration Therapy. It should be emphasized that in this system approach, all the elements are important and are interdependent; the technology is necessary but not sufficient to produce the desired clinical results. Both therapist and patient must play active and special roles.

Collaboration Therapy Technologies

Videoconferencing

Videoconferencing allows the therapist to enter the patient's setting, which is typically the home but can also be work and school. Therapist and patient sit at their respective desks in front of their computers (Figure 2). Videoconferencing allows the patient access to brain injury rehabilitation services when it is impossible or problematic to travel to the clinic. The technology allows the patient and therapist to see and hear each other. Videoconferencing typically uses the camera and microphone built into the computer and mobile hardware, and uses the Internet and HIPPA-compliant software. Today's residential Internet subscribers have much faster Internet speed than is needed to get full-motion HD service with excellent sound and lip-synch.

Figure 2. Therapist in clinic; Patient at home, work, school, etc.



Computer-Supported Cooperative Work

The second CT technology that enables patient and therapist to work together at a distance is computer-supported cooperative work (CSCW). Brain injury therapy requires cooperative work. At a minimum, the patient should be keyboarding information into the computer and for this therapy, there are advantages when the patient and therapist can view the same screen. Each person uses his or her own computer, and each sees the same window on their screens. Each has the ability to type in that window. Everyday activities involve planning, preparation, organizing, and perhaps rehearsal, no matter where the activity ultimately takes place can be included in this cooperative work. Typically, therapist and patient work on a planning and organizing task that is part of a patient-priority activity. The therapist and patient hold a conversation. The therapist asks guiding questions that help the patient think through what needs to be done. The therapist plans, thinks, and talks, while the patient plans, thinks, talks, and types. Note that when the therapy session ends, the patient will be able to seamlessly continue working on the activity.

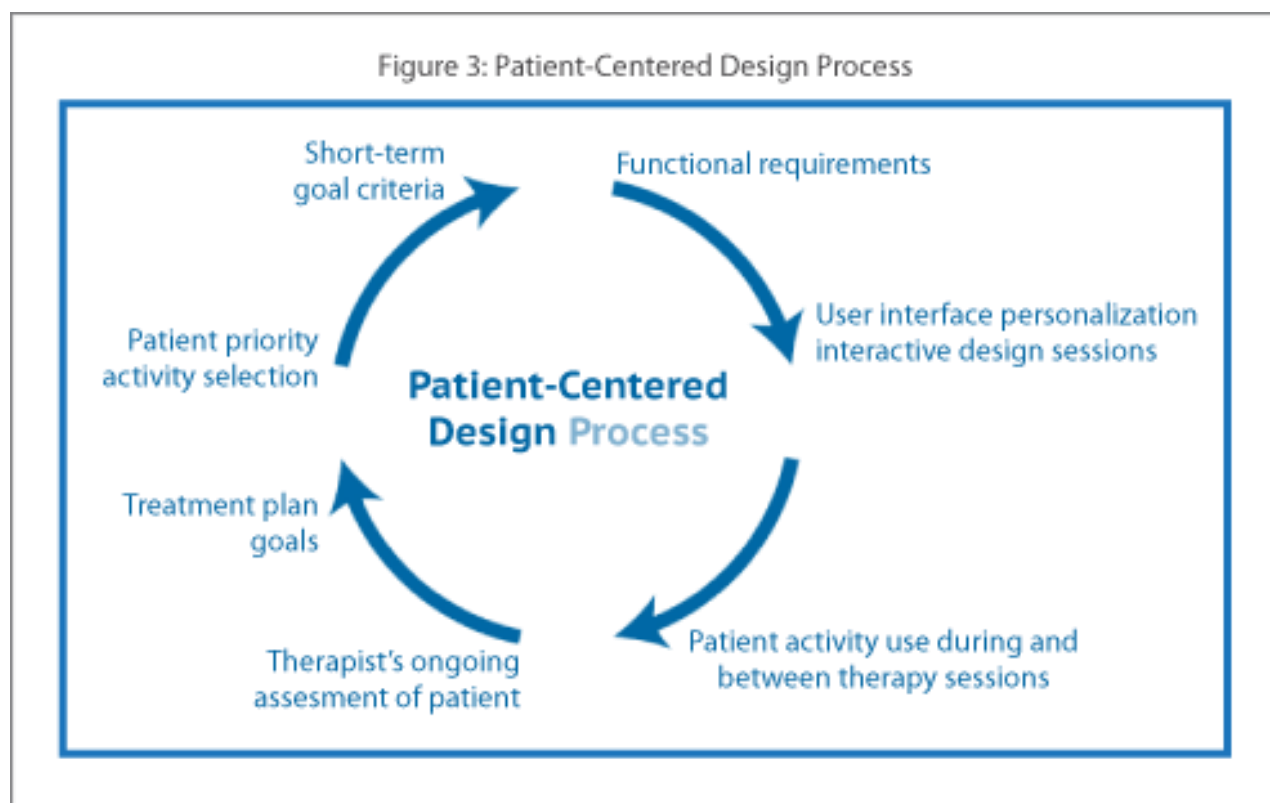
Highly Customizable Personal Productivity Software

The third kind of CT technology designed and created by ICP is the highly customizable personal productivity (HCPP) software suite that the patient uses during the therapy session. Patients with cognitive deficits from TBI/ABI typically have difficulty using computing devices with traditionally-installed software, because their injury has reduced their ability to scan and select the many choices with “ordinary” software. HCPP software is designed to serve the special needs of cognitive rehabilitation therapy patients. It is customizable in minutes, providing the good fit that makes it intuitive to the patient and therefore requires no training time. Because of the uniqueness of each patient’s injury, each patient’s cognitive prosthetic software is unique. This software provides cognitive support for the patient in performing goal activities.

Patient-Centered Design

The fourth technology is “Patient-Centered Design” (PCD), an iterative process which integrates the process of selecting therapy goals, customizing software to support those goals, the role of the therapist, and the role of the patient (Figure 3). The process is adaptive and evolving. With the accomplishment of each patient-priority goal, the patient is at a different place, generally with a somewhat higher level of functioning and using new skills. At that time, therapist and patient can take a fresh look, selecting a new goal that is a priority for the patient.

Figure 3. Patient-Centered Design



The PCD process begins with the therapist's evaluation of the patient, which will be the basis for ongoing assessment later. The evaluation is conventional and results in a report and treatment plan. In the assessment, the therapist identifies patient strengths that emerge in addition to the more typically identified patient deficits.

Observing the patient in the home (and/or work or school) setting gives the therapist a different picture of daily functioning than in the clinic and allows this fuller assessment. The next step is developing treatment plan goals, both long-term and short-term, as in conventional rehabilitation.

An important difference is that the patient-centered treatment plan is operationalized by selecting a patient-priority activity as a short term-goal. This involves the therapist soliciting several suggestions from the patient and then selecting an activity that is clinically appropriate. The therapist then defines the patient-priority activity as a short-term goal and establishes criteria for the successful attainment of the goal. Then the therapist identifies the software features that the patient will need to use in order to successfully complete the activity.

The patient with cognitive disabilities has a critical role in the customization of his or her software. The user interface is the most important design area for software for individuals with cognitive disabilities. Brain injury patients have shown the important ability to be able to specify the design of their user interface so that their software is intuitive to them. This ability can elevate patients to the role of co-designers of their software and can allow them to be active in their rehabilitation. Because customization is so easy, patients may wish to make refinements to their design, and they are encouraged to do so. It truly gives patients ownership of their system, and they are very proud to see their unique design on their computer. Objectively trivial changes in the user interface can have a dramatic impact on usability, especially for the individual with cognitive deficits.

Once the user interface is designed, patients can immediately begin to use the cognitive prosthetic software, beginning with a therapy session. The therapy session focuses on each patient's high-priority activity. (More than one session may be necessary at this stage.) In essence, cognitive rehab therapy is being superimposed onto the patient's life. It is much simpler for a therapist to work with an activity in the context of a specific upcoming event in the patient's life. A specific event offers more available details than a more general or generic activity. The therapist and the patient hold a conversation. Typically, the patient isn't able to answer some questions and needs to ask someone not present for information. The patient may make a list relating to the event. Part of the list may involve information to be obtained, and part may involve planning for the event.

As the therapy session winds down, the therapist gives the patient an assignment that will move the activity forward between therapy sessions. The patient is able to pick up rather seamlessly from where the therapy session left off and work independently because the relevant information remains on the computer screen from when the patient and therapist were interacting. This transition is important, because the goal of therapy is

to give the patient tools that he or she can apply independently. Patients generalize the use of these tools by applying them to other activities in their lives.

After some therapy sessions, the patient will have achieved the short-term goal, and the cycle will begin again.

Outcomes

ICP's patient population consists exclusively of patients who have plateaued in one or more other cognitive rehabilitation programs. The vast majority are patients who have been 3+ years, some 1½ years, and one was 7 weeks post injury.

Clinical Outcomes

Approximately 80% of ICP's patients have been able to achieve a substantial short-term goal in 1 to 2 weeks, and the progress continued thereafter (for a summary see Cole, 2013). A few patients had clinical gains that are suggestive of a brain plasticity mechanism (see *Case Studies*). Approximately 20% of the patients were failures who generally could be identified during the first two weeks.

Most brain injury patients are able to resume their lives after conventional in-clinic rehabilitation. There is no suggestion that Collaboration Therapy provides better outcomes for these individuals. However, for plateaued patients, Collaboration Therapy appears to be superior to conventional therapy. Also, for individuals who cannot attend in-clinic conventional therapy, Collaboration Therapy is appropriate for their cognitive recovery.

Service Offerings

Collaboration Therapy and telehealth are especially appropriate for two kinds of programs:

High-achiever patients

High-achiever patients are individuals who by their occupation, education, or avocational activities have attained a high level of accomplishment. These individuals often have a substantial level of determination and are used to having control over their activities. Collaboration Therapy is ideal for them because they want to set their own agenda and play an active role in their recovery. These individuals often have difficulty in conventional rehabilitation programs.

Patients who have plateaued in other programs

Many patients feel that conventional therapy has failed them and that they have abilities that remain untapped. Most therapists have had patients they believe to have promising potential but only limited (or no) success with the therapy tools available to them. Collaboration Therapy can often offer new tools to augment patients' abilities, quickly demonstrate patient progress, and substantially increase degree of recovery.

Competition with Peer Programs

A service based on Collaboration Therapy would distinguish a facility from local, regional, and national competitors. We would anticipate a warm reception for a High Achievers program.

Financial Outcomes

A program based on Collaboration Therapy costs less to produce than a conventional rehabilitation program. We anticipate that a pilot program would turn cash-flow positive in Q1, turn cumulative-revenue positive in Q2, and have a gross margin of about 17% in Year 1. Because of the substantial learning curves associated with CT, gross margin in Year 2 is estimated to be in the 30% to 40%+ range.

Discussion

CT makes telehealth practical for brain injury patients, therapists, and facilities. The telehealth model assumes a therapist in the clinic and a patient at home, in contrast to the patient travelling to a satellite facility.

CT relies on interplay among therapist, patient, and technology. The interaction and interplay among the three components of the CT model, therapist, patient, and technology, create a new environment for cognitive rehabilitation. CT adds technology as a core element of therapy delivery. Technology provides the CT therapist with a far richer and more adaptive environment, and more therapy tools and techniques. Similarly, CT patients use a far richer set of tools than is available in conventional in-clinic therapy. All rehab programs have had computers for decades, but their use has been as an adjunct to therapy, not a core element.

Telehealth allows the therapist to enter the patient's setting. A key function of CT's technology is to give the therapist in the clinic the ability to virtually enter the patient's home, work, or school. This greatly increases the effectiveness of Functional Rehabilitation. It becomes practical to have the patient's actual priority activities become the focus of rehabilitation. Working in the patient's setting gives the therapist the opportunity to learn the critical details of these activities in the context of a specific event in the patient's life. In contrast, in-clinic therapists can get into the lives of their patients only in limited ways since their access to patients is circumscribed by their access to the patient during scheduled therapy appointments in the clinic rather than whenever the patient needs assistance.

CT is normalizing for the patient. The patient is at home, sitting at his or her desk, using computer software. The patient is having a conversation with the therapist, and that conversation is about an activity that is important to the patient but that the patient needs help in performing. The therapist is asking the patient questions, and the patient is answering those questions, sometimes with a lot of certainty, sometimes not. The therapist can see the on-screen window in which the patient is working. From time to time, the patient types something into an app, and both therapist and patient can see the progress being made. They are not working on an exercise illustrating principles that can be abstracted and applied to a patient activity; they are working *directly* on the activity. As the therapy session comes to an end, the therapist gives the patient an assignment—which gets written down (entered on the computer screen)—that will help the patient move the project forward. The therapy session ends with the closing of the videoconferencing software but not the screen worked on in the session, and the patient leaves the desk. A while later, he or she returns to the desk and computer. The project remains on the screen, along with the assignment, and the patient picks up where he or

she left off. A bit later the patient typically thinks of another activity and realizes that the same software and therapy tools can be useful for this activity as well.

Freedom from travel has important implications. A number of possibilities arise when neither patient nor therapist needs to travel to rehab. Perhaps the most interesting possibility is variable-length therapy sessions that can increase the productivity of both therapist and patient. A patient's cognitive stamina varies within a day and between days. The therapist may decide to break up one day's therapy into two or more shorter sessions. Also, the patient can contact the therapist to ask for a brief session to resolve a problem. Variable therapy sessions can allow therapists and patients to develop a closer relationship and greater skill at working with each other. The patient can continue to work with a therapist within a more structured schedule, but, when the patient faces a crisis needing intervention, a CT session can quickly take place. Because of the therapist's long and deep relationship with the patient and the ease of connecting, the therapist may be able to help deal with the crisis quickly. CARF has had concerns about the ability of programs to monitor patients after therapy has wound down, and quick and flexibly timed follow-ups could help in this regard.

Some skills are more important than others for the CT therapist. The therapist's most important skills do not involve being tech-savvy or a computer expert. Instead, basic therapy skills are critical, including the ability to design a compensatory strategy that the patient can successfully use. The therapist must also be able to identify which patient-priority activities are likely to be good options for the patient at the present stage of recovery. A good therapist can be taught the technical ropes relatively easily. A computer expert cannot easily (if ever!) be taught to be a skilled therapist.

CT uses a patient's priority activities in everyday life as the focus of therapy. During the therapy session, work is being done on an activity important to the patient. At the end of a therapy session, the patient is given an assignment—homework—geared to moving the activity forward. Therapy is intended to make the patient more independent. Early in therapy the patient may need an assignment for between-therapy activities. However, rather quickly, the patient typically begins to apply the skills taught in therapy and use the cognitive prosthetic software to work on other activities in his or her everyday life. The process continues, and the patient becomes ever more able to perform activities self-sufficiently that had previously required caregiver assistance.

Telehealth expands the catchment area without satellite facilities. Creating satellite facilities is the principal strategy that providers use to increase the size of their patient population. Telehealth presents an alternative strategy, one that is not dependent on having to attain a specific market share in a geographic area. Because the inpatient catchment area is greater than the outpatient catchment area, a telehealth offering becomes a way of retaining those inpatients who are too far away from an outpatient location. A High Achiever telehealth program would likely attract patients from around the US, as well as some international patients

Case Studies

The following seven cases provide a deeper understanding of the applications and implications of Collaboration Therapy. These case studies represent a range of diagnoses, a range of functional problems, a range of personal and family situations, and a common modality of therapy that could address each patient's needs. Each case study patient is indicated by 2 initials. Some of the case studies have a designation after the patient initials.

Legend

"High Achiever"

An individual who has achieved recognition of superior accomplishments through superior occupational achievement, avocational achievement, or educational achievement.

"High Functioning"

A discharged patient who has succeeded at rehabilitation in the clinic, attained a normal level of cognitive functioning on a relevant test, but has begun to fail in performing everyday activities at home or work.

"Suggestion of brain plasticity"

Reserved for those cases where the patient has made an extraordinary recovery of function as a result of ICP's therapy and which seems to be best explained as an instance of brain plasticity. Proving brain plasticity is beyond the scope of our work.

Case #1: LC – Recovery from severe/profound cognitive and physical disabilities from stroke. High Achiever; suggestion of brain plasticity

Presentation at the 1994 NIH Neural Prosthesis Workshop, October 19-21, 1994

Note: Computer-Based Cognitive Prosthesis (CBCP) was a forerunner of Collaboration Therapy.

A previously well 33 year old left handed woman experienced several months of repeated episodes of neurologic dysfunction of unknown etiology. Despite frequent and chronic anticoagulation she suffered several venous strokes that left her with damage in the putamina, corona radiata, subcortical white matter, pons and pontomedullary. After her final TIA, a hematologic consultant discovered polycythemia vera, she was treated with hydroxyurea, and since then has had no further strokes.

She was left with a neurobehavioral syndrome manifested by executive

dysfunction; poor information retrieval; visually guided constructional difficulties; unilateral neglect with shifting laterality, dominantly left sided; slowed information processing; impaired ability to manipulate several pieces of information simultaneously; impaired visual and verbal memory for new information; impaired language, including reading and word retrieval; impaired arithmetic skills; and bilateral, right more than left, spasticity and dystonia resulting in spastic circumductive gait and spastic contracture in all muscles of her right upper extremity. Areas of strength were the ability to verbalize her thoughts and ideas; insight and the ability to benefit from supportive counseling; strong motivation and tenacity to improve her level of functioning; and broad interests.

The impact of these deficits was profound. Premorbidly, she was a talented and successful fashion designer. After the strokes she was deprived of the dignity of privacy, both physically and mentally. She was reduced to no use of one hand and only limited motion and digit control of the other. She was unable to independently perform many activities of daily living, such as toileting, bathing, dressing, and eating - and had to depend on her parents or a companion for assistance. Written expression was important to her but anyone scanning her notepad could read her thoughts; writing was also both painful and tedious. She was unable to read more than a few sentences at a sitting, and spend much of her unstructured time watching television. Her rehabilitation history is extensive, and includes in-patient, day hospital, community re-entry, and comprehensive outpatient services of cognitive, physical, occupational, recreational, speech and psychotherapy. At the time of this intervention, no further cognitive rehabilitation was said to be indicated despite substantial cognitive deficits.

METHOD

This is a single subject case study with a quasi-experimental design. A Computer-Based Cognitive Prosthesis (CBCP) was introduced as an intervention to compensate for deficits preventing her from performing a type of activity which she desired to perform. Her CBCP has targeted two major activities: first, writing; and a month later, graphic design. User requirements were defined and a prototype developed. Human Factors usability testing was applied to identify and resolve design errors. A key performance goal was to use a prosthetic application self-sufficiently on delivery. After delivery, software was modified to resolve new design errors and to provide new features.

RESULTS

The intervention's goals were met and substantially exceeded. A number of functional improvements occurred, some in the neurocognitive area and some in the neuromotor area. There were measurable improvements in spelling and grammar within two weeks. Also, within the first few days, perseverance and stamina for reading and working on cognitively demanding tasks markedly improved to the point that the patient was able to sustain effort for 3-5 hours per session.

Unexpected improvements in visual scanning and reading were also observed. Initially she required double spacing for all text. After three months her visual scanning improved so that single spacing was sufficient. In addition, she became able to read

100 book pages in three hours.

In the neuromotor area, there have been marked improvements in hand control which suggests generalization. She is now able to toilet independently at night, and during the day when she wears accessible clothing. She is now able to bathe herself, and to shampoo her hair. She is also able to dress herself, depending on the outfit. She can now hold and eat finger foods such as a sandwich or piece of fruit. Thus, the intervention afforded her a degree of privacy, control, and independence that she had not experience since her illness.

Use of a mouse (for the graphics program) proved a challenge for her, and she spent many hours experimenting with it, learning how to control it. It was also remarkable for her, given the neuropsychological findings, to be able to produce and rotate 2-dimensional design by translating her hand movements through manipulation of the mouse.

Improvements were also seen in the follow-up behavioral neurological examination. Six months after the intervention began, she enrolled in a college continuing education course.

DISCUSSION

These findings show that this patient's level of functioning has increased during the time she has used her CBCP. Improvements occurred in areas targeted by the intervention, but more significantly, in areas not directly targeted by the intervention. The magnitude and breadth of these changes in this patient is striking, given the severity of brain damage she suffered, the time elapsed since her strokes, and the prior rehabilitation efforts. These improvements are contemporaneous with the intervention and cannot be easily attributed to other explanations such as spontaneous recovery or lack of rehabilitation.

Improvements in non-targeted behaviors were first reported by the patient two weeks after the intervention was introduced, and have continued. This strongly suggests that her use of the CBCP, which targeted reading and drawing behaviors, produced generalization or a process akin to generalization. An especially striking example of this is the increase in level of function for visual scanning and reading. At the beginning of the intervention, which was designed to improve her writing, double spacing was required for reading the computer screen and printed text. Her reading sessions were laborious and brief. While her writing improved as planned, she also became able to read single-spaced text on the screen, and can read books and magazines for hours with increased accuracy, comprehension, and of course, sustained attention.

In our lab, we have seen a number of other cases where patients, long after a brain injury and who were believed to have limited rehabilitation potential, have experienced increased functioning in areas not directly addressed by their CBCP interventions, in addition to rapid achievement of targeted goals. These results are generated by patients functioning in their natural environment and performing

compound and complex tasks. These results have implications for plasticity of the damaged brain.

Epilogue

The keynote speaker to the workshop where this case was presented was Michael Merzenich, PhD, one of the world's leading experts in brain plasticity. Over lunch, he said that brain plasticity was the most likely explanation for the patient's outcomes, and that I should feel free to attribute that to him.

LC continued therapy for another for another year. Her level of physical, cognitive, and emotional functioning continued to gain, and she was able to use Microsoft Office software with minimal accessibility adaptations. Physically, is able to walk short distances with a cane. She is married and living an independent life which

Case #2: JR – Destined for a group home and sheltered workshop after a TBI, she was able to graduate from college. Patient treated via telehealth in 3 locations

JR was a 22 year-old right handed woman, 18 months post TBI. She was a rising college senior when while jogging she was struck by truck mirror. Medical complications followed including meningitis and shunt problems, which further decreased her cognitive abilities. A year later she was discharged from inpatient rehab to outpatient rehab and home, where she needed substantial caregiver support throughout the day. Her deficits included short term memory, slowed information processing, difficulty learning new information, distractibility, and broad executive dysfunction. She needed constant cueing during the day, including eating and toileting. Strengths included good social skills, a pleasant demeanor, an athlete's persistence and physical exercise. Her family provided her with very substantial support, and they lived in a small town where she also had substantial social support. At 1 year post injury and following extensive inpatient rehab, it was not anticipated that she would be able to live independently, and her prospects were for a group home and sheltered workshop.

Outpatient cognitive rehab was provided by a speech therapist who had collaborated on a number of patients with ICP. The therapist felt that ICP's scheduling tools might be appropriate for JR. She needed constant cueing during the day, mainly from her mother. They were very close, and there was no problematic tension between them, however, the therapist knew that JR would prefer to rely less on her mother for cueing. ICP's CellMinder, linked to the calendar, delivers a cue to the patient in her own voice and in a timely manner. CellMinder worked well, and slowly gave JR a sense of more control over her life. Her life was based in the community, getting together with people, physical therapy at a gym, daily cognitive telerehabilitation, watching local high school sports, and reading.

Months later, the therapist felt that the combined effort of therapy, family, community and an athlete's determination had substantially increased JR's level of cognitive functioning. It was decided to explore the possibility of a return to college.

The response was that that JR would need to pass competency tests in 5 academic areas. The family felt this was potentially life-changing with no real downside risk. Also it would give her therapy a sharper focus. New academic support software would need to be developed for JR. The speech therapist, whose practice included academic support for learning disabilities, outlined the software features that would be initially needed, which included aural, visual, and tactile learning elements. The application was a concept-learning module. JR was already using a cognitive prosthetic word processor. Of course the calendar and CellMinder helped provide schedule and structure.

JR and her therapist worked at relearning her college coursework. Some of the time JR worked with her therapist, some of the time with her mother, a former teacher, and of course, a lot of time she worked independently. There were texts and workbooks that were used in the long process of relearning a number of courses in 5 areas. At the end of 2 years of effort, she had successfully passed her competency tests, and had gained readmission to her senior year. Her senior year she lived on campus.

Her speech therapist continued to provide her with academic support. She would complete her senior year in a single academic year. Following graduation, she passed the national competency exam for her chosen profession.

During these 4 years of therapy, the therapist was able to provide JR with therapy along the outpatient continuum. Telerehabilitation methods made it easy for patient and therapist to have sessions. During that time, JR found herself at 3 different locations in 2 states. More important though was the continuity of care that the telerehabilitation therapist can provide, the therapist's deep knowledge about the patient, and the subtleties of her cognitive functioning. Telerehabilitation means that a patient and therapist can continue to work together even if the patient moves. The relationship between JR and the therapist is an extremely close one, and they have shared so much. From this perspective it is more efficient to have that continuity than to have to build new relationships. It is typical for patients to move from one outpatient program to another, under the theory that different programs have different specializations. In practice, programs never finish all the issues that they hope to deal with, and the more difficult ones are the ones that slip through the cracks. When therapists need to address the entire continuum, the important issues necessarily need to be dealt with, and can't be passed on to the next program. And the patient gets to achieve the maximum level of functioning.

Many elements came together to change JR's path following discharge from inpatient rehabilitation. This would include a supportive family, an insightful therapist, and technology-based rehab therapy. It is also likely that JR's competitive spirit, her desire to achieve her goals, played a role. She is too young to be considered a High Achiever, and high achievers do have a strength that helps them succeed.

Case #3: PD – An executive was able to return to his career, even though shopping at a convenience store was challenging - High Achiever living in Metro-New York

PD was a 61 year-old right-handed man, 7 weeks-post TBI. He was a senior vice president of a multi-national bank, and graduate of Harvard. ICP was his third and final rehabilitation program. He had been bicycling down a hill wearing a helmet (which saved his life), and was thrown 30 feet. He was in a coma for a week, then spent several weeks in a prestigious outpatient “day-hospital” program (6-hours a day, 5 days a week). The day hospital program had him doing typical functional exercises that were both irrelevant and difficult for him, and he didn’t feel that the therapists were helping him to work through the exercises. This program was a bad fit for him, notwithstanding its reputation, and he left. He next went to a local neuropsychologist. Among other things, she gave him an assignment to select any article in *The Wall Street Journal*, read it, and list 5 important points in the article. He has read *The Wall Street Journal* every day on the train to work. This was background information for him; he never consciously noted important points though he might see articles to chat with others about. He felt he would be graded by the article he selected (no), and by the points he selected (only to the extent of their importance). She was very close to the mark, but still far enough away to be counterproductive.

In the 8th post injury week his insurance company referred him to the Institute. In the initial interview and evaluation, he was in the typical cognitive fog. He was able to carry on a conversation, but had difficulty answering many questions about his life, and was slumped in an arm-chair. However, when the conversation turned to his work, he sat up, his body language changed and his speech changed. He was able to answer questions in detail, with confidence in his voice, and with changing intonation in his voice. This was a different person. He explained that his profession was his most important and most satisfying activity, and present and former colleagues and coworkers made up many of his friends. His wife took care of most of the household support activities.

The Institute’s approach is patient-centered. He and his wife had many friends and colleagues, who wanted to visit. PD wanted an application which would show who was scheduled to visit and when, and who had already visited. This application he could view, but he didn’t do any data entry; family members would do the data entry. PD was pleased with this, and would consult it frequently during the day. He enjoyed the steady stream of visitors and was increasingly social in his interaction with them.

He also expressed an interest in seeing his friends and colleagues at work. Rehabilitation therapy had been isolating for him. It was arranged for him to go into work a couple of hours a day, a couple of days a week. One day he happened to be there when the weekly portfolio review meeting was taking place, and sat in. He didn’t speak, but commented to his therapist that he had no trouble following what was said. This was a seminal event in his therapy and recovery, and framed the rest of his treatment. Cognitively, he had presented as 2 different people at his evaluation. And at a relatively early point in his recovery, he was describing a very high level of cognitive functioning in his occupational area, at the same time that he could not go a neighborhood convenience store and buy a quart of milk. In conventional cognitive rehab, PD’s inability to go to a convenience store would stand in the way of approaching his occupational potential. In contrast, with a Collaboration Therapy approach, his interest coupled with the suggestion that he was able to follow the meeting, suggested that his profession should be the priority of rehab. It was decided that he should attend the weekly portfolio review meeting, and

perhaps increase the number of days he went into the office.

As for reading material, we had the benefit of learning from others' mistakes. It was decided to have him read the weekly briefing book, which had the portfolio of large loans and a current narrative. He received a copy a few days before the weekly meeting. His primary therapist was a PhD psychologist had never taken a business course, and couldn't determine if he was correct in his interpretation of the numbers and the text. This became an advantage. They would go through the book together for a couple of hours at a time, and PD would explain its contents to the psychologist. He was reading and explaining, but she didn't need to comment or answer questions. The third week as he was reading and explaining, he suggested that it looked like the bank was fixing its balance sheet in order to sell the bank. His first week attending the weekly meeting, he felt comfortable asking questions and making comments. From the reaction of meeting attendees, he wasn't embarrassing himself, and his comments were often on the mark. He increased his time at the bank, and was then allowed to take on some responsibilities. He was given a difficult project, and was able to do well with it, according to his manager. Not long after the completion of that project, it was announced that the bank would be sold, as he had predicted in this third week of reading the portfolio review book.

By any measure, he is what we would classify as a High Achiever by both education and professional responsibilities. We have found that High Achievers have special needs in their rehabilitation, and PD's case study is an example of that. These individuals are used to having a substantial amount of locus of control in their lives, and bringing a high degree of capabilities to activities that they find engaging. Other facilities do not recognize High Achievers as having special abilities and special rehabilitation needs. Rather, they are set on the same track as other patients, needing to demonstrate their abilities to deal with easy activities first, and then going on progressively to more challenging ones. Indeed, an argument can be made that High Achievers are at risk of doing poorly in conventional cognitive rehabilitation. They are not given an opportunity to show their residual abilities, and they are very likely to run into difficulty with some cognitive skill which has no relevance to their lives.

PD presented basically a bi-modal distribution in cognitive functioning, cognitive fog on the one hand and an articulate discussion of his professional activities. CT places an emphasis on patient priority activities, which directed therapy to his professional activities. CT also suggests that the patient be involved in selecting the materials that will be used in therapy. Reading *The Wall Street Journal* wasn't that far removed from the weekly briefing book from the psychologist's perspective, but it was far removed from PD's perspective.

The goal of cognitive rehabilitation is to restore function to the individual. Typically this is done in stair-step method, with mastery of easier material leading to the introduction of more difficult material. Return to work is considered the final step, where all of the reacquired skills can be applied to this most difficult of tasks. The CT approach is "out of sequence". Return to the workplace had a strong and valuable social component, along with some *exposure* to the cognitive content of work. Additionally, for PD, what was hard was easy, and what was easy was both

hard, and largely irrelevant. In the end – actually long before the end – he was able to show and nurture his cognitive capabilities.

Case #4: BW – Sometimes success in the rehab facility doesn't “travel” home. With telehealth, the patient is at home. “High Functioning” – Patient living in another state

BW was a 46 year-old right-handed woman, 20 months post-TBI. She had spent 9 months in a well-regarded outpatient brain injury rehabilitation program. She had done well in rehab, and had achieved the status of being “high functioning,” by succeeding in all her therapy tasks, and also testing as “normal” after cognitive rehabilitation outpatient therapy. She was considered independent in cognitive household and social activities.

Then she discovered that she was having difficulties with tasks and activities at home. Previously she had kept the financial books for a small family business, and she managed the office operations. This is a syndrome where the patient succeeds in the clinic, but that success diminishes and doesn't transfer to the home.

BW and her therapist decided that letter-writing would be an appropriate place to begin as a therapy goal. She was unable to use her word processing software. Instead, cognitive prosthetic software was customized for her, a 4-function word processor. The therapist and patient worked together productively on a letter that BW wanted to write. The session ended with the expectation that BW would be able to easily finish the letter over the weekend.

On Monday morning, the therapist examined the usage log and saw that BW had spent 2 ½ hours over 2 days working on the letter, and that it had been printed 3 times (See Table 8-4). The therapist couldn't tell what the problem was with BW's initial effort at writing a letter. For that answer, she needed to talk with BW.

Figure 8-4
Data showing 2.5 hours over 2 days

5/30	8:46:00 PM	Select New
5/30	8:46:00 PM	Opened New Document
5/30	10:58:26 PM	Select Save
5/30	10:58:52 PM	Saved As - c:\My Documents\Dot and Joe letter.rtf
5/30	11:16:32 PM	Select Save
5/30	11:16:38 PM	Closed - c:\My Documents\Dot and Joe letter.rtf
5/31	1:45:36 PM	Select Open
5/31	1:45:37 PM	Opened - c:\My Documents\Dot and Joe letter.rtf
5/31	2:04:31 PM	Select Print
5/31	2:04:31 PM	Printed –
5/31	2:08:55 PM	Select Print
5/31	2:08:55 PM	Printed –
5/31	2:22:03 PM	Select Print
5/31	2:22:04 PM	Printed –

She explained that she wanted to make the letter “look right”. That turned out to involve both changing the formatting with spaces and tabs, and checking the spelling.

The therapist suggested a template as a means of addressing the formatting problem. As for spelling, the therapist could add a spell-check feature. She discussed options with BW who agreed that a template would be a good approach, and appreciated having a spellchecker. They developed the template, and designed the user interface for the spellchecker. BW was given an assignment to write another letter using the new features.

The next day the therapist examined the log. This letter had taken 20 minutes in one session to write, spell-check, print, and save (see Table 8-5).

Figure 8-5
Patient log data showing 20 minutes

6/6	7:51:06 PM	Select Open
6/6	7:51:17 PM	Opened - c:\My Documents\Letter format.rtf
6/6	8:08:25 PM	Selected Speller
6/6	8:08:30 PM	Misspelled - NJ
6/6	8:08:31 PM	Skipped
6/6	8:08:41 PM	Misspelled – Raod
6/6	8:08:41 PM	Replaced - Road
6/6	8:08:44 PM	Misspelled - parent-educator
6/6	8:09:00 PM	Skipped
6/6	8:09:15 PM	Select Print
6/6	8:09:16 PM	Printed - c:\My Documents\Letter format.rtf
6/6	8:10:08 PM	Select Print
6/6	8:10:08 PM	Printed - c:\My Documents\Letter format.rtf
6/6	8:11:04 PM	Select SaveAs
6/6/	8:11:30 PM	Saved As - c:\My Documents\Jean.rtf

Therapy continued for a few months. Therapy delivered to the home and addressing patient priority activities filled in areas that her previous therapy hadn't. The cognitive prosthetic software having served its purpose, the patient was moved to MS Word and to Excel, and was able to resume taking care of the finances and the office, as well as the myriad of other tasks necessary to run a home.

"High Functioning" patients, when they encounter problems functioning after discharge, are considered difficult to treat. They have already succeeded at conventional cognitive rehabilitation. Because Collaboration Therapy is delivered to the home, and because therapy addresses the patient's actual priority activities, this modality is able to detect the cognitive deficits in context that conventional therapy misses.

Case #5: RJ – Telerehab in 1992, before broadband; brain plasticity before its introduction to brain injury rehab.

RJ was a right-handed 45 year old male, 6 years post-TBI. Prior to his head injury, RJ had worked as a successful commercial artist which afforded him an affluent lifestyle. He enjoyed a variety of cultural activities and an active social life. After his head injury, he was unable to live independently. His temporal processing was significantly impaired, and he was only able to function with a 2-week window to the future. He was plagued by serious memory problems which made it difficult for him to follow a routine, remember appointments and obligations and take his medications on schedule. He had difficulty shifting from one activity to another during the day.

For three years, RJ had been treated by the same therapists in a leading TBI

rehabilitation program. His therapy addressed structuring and following daily activity patterns, and utilizing a manual schedule as a compensatory strategy. Major problem areas included poor planning ability, impulsivity, poor attention to detail, and inconsistent compliance with daily routine. The clinician had exhausted both conventional and non-conventional therapy approaches. In addition, RJ had developed an elaborate system consisting of several sets of manual scheduling devices. The sum total of these devices was not sufficient to achieve compliance with routine activities, and reduce impulsive behaviors. Moreover, these devices did not provide the structure RJ needed to be able to think in terms of the future. His calendars and journals were archival: they were records of events which already had occurred.

Because of the functional areas in which his recovery had plateaued, he qualified for an NIH funded study. Following the IRB approved protocol, he was informed about the study and its risks, and consented to participate. The goal of the study was to use cognitive prosthetic software to address a rehabilitation goal that could not be attained with conventional cognitive rehabilitation techniques. A computer was installed in his home with communication capabilities.

RJ's goal for the study was to have him follow a daily schedule using cognitive prosthetic software. Daily therapy sessions were conducted in the clinic, with both patient and therapist in the suite. During the session, they used a computer which was connected to his computer at home. Additionally, the therapist found it valuable to have a telerehab therapy session in the evening, from the therapist's home to his home. During these sessions, RJ and the therapist discussed and planned future schedules. This process helped to set an example, aiding in prioritizing, thinking ahead, and being realistic about the amount of time needed for various activities. RJ found the convenience of the remote communications to be very helpful. He remarked that it was amazing to be able to relate this intensely to somebody without physical travel. Once he began to use the computerized daily schedule, he became acutely aware of the computer's impact on his daily activities. He stated, *"The computer is full of surprises... 'I am feeling more punctual, more on target'".*

RJ's interactions with the computer became more relaxed and comfortable, and he required less supervision. He demonstrated more patience, increased frustration tolerance, and the ability to delay gratification. He became more independent in problem-solving, sometimes attempting to circumvent a systems problem with a creative solution. Some of these solutions evolved into new intervention goals. One outcome was remarkable. RJ's planning horizon at the beginning of the study had been two weeks. One month into the study his planning horizon had increased 4-fold to 8 weeks. In the mid-1990s, the brain injury rehab field saw no medical expectation of cognitive functioning improvement 2 years post TBI. Two decades later, while preparing a book on TBI and telerehabilitation and reviewing this case study, it seemed that some kind of brain plasticity process was a possible explanation for that outcome.

The computer log report showed that during the first month, he printed his schedule every day. He also checked as completed at least one appointment every day but one. From a total of 220 appointments during that period, he marked 82% with a check mark to show completion. He also had a total of 402 items on his "To Do" list

associated with the 220 appointments. From these, 79 appointments had at least one “To Do” item associated with them. He marked 84% of the “To Do” items as completed or cancelled.

RJ’s ability to focus on relevant details improved steadily. He was impressed with his ability to take note of what was on the screen, what used to be on the screen, and what ought to be on the screen. Likewise, the structure of the schedule helped him to focus on one activity at a time, and caused him to improve his compliance and punctuality for appointments. He mentally divided the day into “target zones”, a portion of the day which, in his mind enabled him to refocus and redirect his energies at the start of each new zone, giving him several fresh starts a day.

At the end of the study, he was diagnosed with a late stage aggressive cancer. Funding was provided to continue his participation with study resources. He received surgery and then radiation therapy. He was also given narcotics for pain. His life had become more complicated with medication and with medical appointments related to his cancer treatment. His primary therapist noted that for a couple of months of cancer treatment including narcotics, he seemed to have the same if not more focus on his activities. Unfortunately, he died three months later.

Case #6: JM – 2 major rehab facilities couldn’t restore episodal memory or key executive functioning. ICP did. High Achiever, Suggestion of brain plasticity – Patient in Massachusetts

JM was a 56 right-handed male 18 months post cerebral hemorrhage. At the time of his stroke, he was a corporate executive managing 4000 people and was a graduate of an Ivy League college. For 15 months he had received cognitive rehabilitation at 2 leading facilities, and there had been little change over the past several months. His stroke had affected his episodal memory as well as his ability to plan activities and manage a schedule. He could remember almost nothing of what he had done, or what he was supposed to do. His language, personality, emotions and other mental capabilities were untouched. He was very pleasant in conversation and retained a sense of humor. He lived in an exurban home, and had a vacation home as well. Both he and his wife had enjoyed active outdoors activities.

When he entered the Institute’s program, he could be safely left at home alone for less than an hour, but he would not be able to accomplish much, or even prepare simple breakfasts or lunches. JM and his wife were both active in their church, and he was able to do tasks there with supervision, and enjoyed greeting people for services and events. His wife, with experience in dealing with cognitive disabilities, had tried to provide him with organization strategies using calendars and “To Do” lists, but they would get lost.

As for goals, his wife hoped that he could become self-sufficient during the day, and that she could continue her activities with her friends. They would also go to their vacation home. JM wanted to be able to succeed at performing some activity at home. The initial goal was for JM to be able to perform some activities self-sufficiently for several hours a day, with no direct supervision. He was handy around the house,

and small projects could be organized. The Initial Intervention would be for JM to be able to follow a simple schedule and perform a few activities he enjoyed each day.

The prosthetic application began with a calendar for the day, and a few activities for him to do alone, and he would have short telerehab therapy sessions several times a day. He would carry his 1-page schedule with him, make notes on it, and could print it out again when it was lost. He would also update it during the day, showing what had been done. Most of the initial projects were in the house or yard. The common element seemed to be that he enjoyed them, and they were not complex. His wife helped to suggest activities and projects, and observed him as well.

Activities expanded to chores in the church during the week. He would often work on some project with another church member. He began remembering some details of the activities he performed, talking about them to his therapist. His wife became comfortable that she could leave him alone for an hour and then 2 hours. He would find things to occupy himself, and also became more active.

He responded well to the initial intervention. He was able to keep track mainly in writing of his activities, and entered them into the calendar later.

He would not be returning to work, but he was curious about his ability to work on some technical activity. A coworker suggested an actuarial problem that he would have been able to do, and prepared a copy – a complex Excel spreadsheet – for him. JM worked on this with his therapist, using the same approach as with PD's weekly report. JM worked on the spreadsheet, talking to the therapist, which took many sessions. JM worked on the problem for one to two hours at a time, long sessions, but it had captured his interest. "Working memory" is what people use when they are working on an activity. Information in working memory is seen as expiring after 20 or 30 minutes. One to 2 hour sessions are way beyond the timeframe of working memory. Somehow, JM had the ability to manipulate the information in and about the model for an extended period of time. He was able to solve the problem, and it gave him a major feeling of success and accomplishment.

And somehow along the way, JM's episodal memory improved, as did his memory for events of the day. He began to drive, and in a matter of a couple of months was able to drive an hour into the city and navigate traffic there. He had become able to go off for the day and return in afternoon.

JM was a high achiever. He was used to having a lot of control over his activities, and selecting what he would attend to. Collaboration Therapy enables the individual to choose their priority activities, and have their therapist support them on those activities. Additionally, cognitive prosthetic software provides cognitive support for the individual. What is noteworthy is that JM was able to recover enough episodal memory, and enough prospective memory to become completely independent in his retirement activities. Given his rehabilitation history and the amount of time that had passed since his stroke, his gains seem remarkable, and are at least marginally suggestive of a brain plasticity process at work.

Case #7: BD – Unusual executive functioning deficits successfully addressed by therapy coupled with customized technology

BD was a 46-year-old right handed woman suffering from solvent-encephalopathy three years post. Solvent encephalopathy is similar to TBI in that involves diffuse damage to the brain from organic chemical vapors. In BD, it manifested itself in broad executive dysfunction, affecting not only planning, organization and problem solving, but also an inability to respond with action to upcoming events. She would be aware of an event, and the consequences of her inaction, but unable to link the two together. Conventional cognitive rehabilitation therapy had been largely ineffective.

Therapy began with a list of upcoming events. One of those was the beginning of the school year for her children. This was selected because of its importance for framing the upcoming year. On the other hand, it is a compound-complex activity extending over weeks, involving some tasks with limited control (scheduling doctors' appointments), some which needed to be completed before school began, and some which could slide until after school began. Therapy sessions involved identifying the many tasks that needed to be done, what those tasks involved, finding time for her to do them, and making sure that she did in fact do them.

The therapist discovered that one of the patient's problems was difficulty in structuring tasks. Word processors are excellent tools for structuring tasks, and therapy sessions are critical in its success. Collaboration Therapy sessions are basically a conversation between therapist and patient structuring what needs to be done. Preparing for the beginning of school is well-structured and well-understood. In Collaboration Therapy, the therapist doesn't tell the patient what to do, rather she asks leading questions so that the patient comes up with the answers. Using a word processor, the patient types in the specifics of what needs to be done for all the children, as well as for each child. For example, a medical form needs to be filed, which requires a doctor's appointment, which needs to be scheduled, and she and the children need to be available at the appointment time.

A word processor is an excellent tool for this kind of planning. The patient will spontaneously think of items in a non-linear fashion. With a word processor, the various tasks needed for the event can be listed and separated along the page. As the patient identifies more details, she can move the cursor – with guidance from the therapist – to the location in the process where it should go. In this way, the word processor supports her non-linear thinking, and the document that emerges is a linear well-organized structure of what needs to be done. This is a living document, as the patient begins to schedule subtasks, and as more details emerge.

The Calendar-Schedule is used to plan for when and where these many tasks will take place. Cell-Minder is the therapy tool BD could use to give herself reminders during the day. Beginning the first day of therapy, BD was working between therapy sessions each day. She was able to experience early success with the scheduling of the doctor's appointments, and then the series of successes that accompanied each of the tasks that were part of the complex process. When something didn't go smoothly, it was a learning event which could help get things back on track.

The therapy modality was successful in having the patient in the complex task of

preparing her children for school. Therapist and patient had established a working relationship which continued. BD had daily therapy sessions, and she added other activities to her schedule, even before completing the school preparation. She saw how different software features could help her. She would ask for those features which were quickly customized and added to her software. Her level of cognitive functioning was increasing rapidly and along with that, her level of self-sufficiency. Therapy sessions took on a different flavor as she described to her therapist what she had been doing, and how she was able to address more activities in her life. The therapist continued to provide insight to BD. BD was able to be discharged after 4 months.

Conclusion

Collaboration Therapy (CT) is directed toward patient populations that are appropriate for a tele-rehabilitation service. Tele-rehabilitation service criteria include 1) patients who have plateaued in conventional in-clinic therapy; 2) inpatients who are too distant to an outpatient facility; and 3) individuals with TBI/ABI who are in unserved or underserved geographical areas. Tele-rehabilitation service is also valuable for High Achieving individuals – by occupational, avocational or educational achievement – who will often have difficulty with conventional rehabilitation. This group has shown considerable success with ICP's therapy.

CT serves the outpatient continuum of care, from a half-day hospital program on down. CT in a tele-rehabilitation service greatly expands the catchment area, providing an alternative to the satellite model.

CT is a modality of brain injury tele-rehabilitation that creates an active relationship between the patient, therapist and technology in a therapy process. Computer technology supports the therapy, enables the therapist to use and develop new therapy techniques, scaffolds the patient to access greater abilities, which allows the therapist to address higher level issues.

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